Identifying Stigma: The Road to Lung Cancer Advocacy

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This research uses a grounded theory approach to develop theory on stigma in the lung cancer experience. Lung cancer is the number one cause of cancer death in the United States. In 2009 alone, approximately 219,440 people were expected to be diagnosed with this disease; over 159,000 would die (American Cancer Society, 2009). Putting this into perspective, more people die of lung cancer each year than breast cancer, prostate cancer, colon cancer, liver cancer, kidney cancer, and melanoma combined. Though progress has been made for other cancers, the prognosis for lung cancer continues to be very poor (Ries et al., 2005) with seventy percent of those newly diagnosed at the advanced stage level (Albert & Samet, 2003).

Regardless of the high incidence and mortality rates for lung cancer, resource allocation for this disease remains low. A look at federal funding suggests that lung cancer continues to get the "short end of the stick." In 2005, federal funding for lung cancer trailed that of breast, prostate and colon cancers by wide margins (Lung Cancer Alliance, 2009). Four years later, the gap widened still as federal funding for lung cancer decreased while funding for breast and colon cancers increased (Lung Cancer Alliance, 2009). Although funding for prostate cancer had decreased somewhat during this period, it remained double that of lung cancer despite a nearly 100% five-year survival rate. In comparison, the five-year survival rate for lung cancer is a low 16% (American Cancer Society, 2010). All told, lung cancer received a mere 9.8% of the 2009 federal cancer research monies compared with breast , prostate and colon cancers which received 54.5%, 19.4% and 16.3% respectively (Lung Cancer Alliance, 2009).

This disparity sends a powerful, negative message to individuals diagnosed with lung cancer; namely, lung cancer is not worthy of funding. Ruckdeschel, Spitz and Saxman (2001) suggest that the low funding is due to stigma associated with cigarette smoking. This research examines stigma in the lung cancer experience in order to develop a theory or set of theories that can be used for lung cancer advocacy.

Methodology

This study used a classic grounded theory approach to collect, analyze and interpret data (Glaser, 2008). The Institutional Review Board of the University of Texas at Austin granted approval for this study and methodology.

Sample

This research taps the experiences and perceptions of expert informants (i.e. oncology social workers) who work with this population. The initial theoretical sample consisted of three oncology social workers employed in diverse oncology settings, who had direct or indirect access to people diagnosed with lung cancer. They included 1) an oncology social worker in a cancer hospital with direct care responsibility for people diagnosed with lung cancer; 2) a social work supervisor in an acute care setting who supervised social workers with direct care responsibility for people diagnosed with lung cancer; and 3) an oncology social worker in a cancer support agency who co-facilitated a lung cancer support groups. Following Glaser's (2008) method of classic grounded theory, a constant comparison of the data began immediately

from this initial sample in order to allow core categories to emerge. Based on these initial findings, the theoretical sample was modified to saturate the core categories.

Thus, the remaining participants in this study included eighteen oncology social workers employed at cancer hospitals located across the United States as identified by the U.S. News & World Report of Fifty Best Cancer Hospitals (2006, 2007). These participants had direct care responsibility for people diagnosed with cancer and their family members. Their work spanned 17 hospitals in 13 states. Their experience with people diagnosed with lung cancer ranged from 3 months to 23 years with the number of lung cancer patients seen per month ranging from 10 to 110 depending on the distribution of their caseload and their employment status; i.e. full-time or part-time. Thus, data in this study represent social work experience with over 25,000 patients with lung cancer during the three years prior to the interview.

Furthermore, the oncology social workers were employed in a variety of areas within the hospital setting. Two provided services to patients admitted into the hospital only, one provided services to patients who were admitted to the hospital as well as those in the clinic. All other participants provided outpatient care in the clinic or through a satellite office. Furthermore, one participant provided care to non-surgical patients only; all others provided services to both non-surgical and surgical patients. Two participants were part-time and one was employed in a temporary position. Six of the participants had caseloads fully dedicated to patients diagnosed with lung cancer. The remaining participants provided services to patients diagnosed with lung cancer as well as to those diagnosed with other cancers. All participants were born in the United States and identified as White/European American. Their ages ranged between the mid-twenties to the early sixties with one third of these participants above age 50. Sixteen were female.

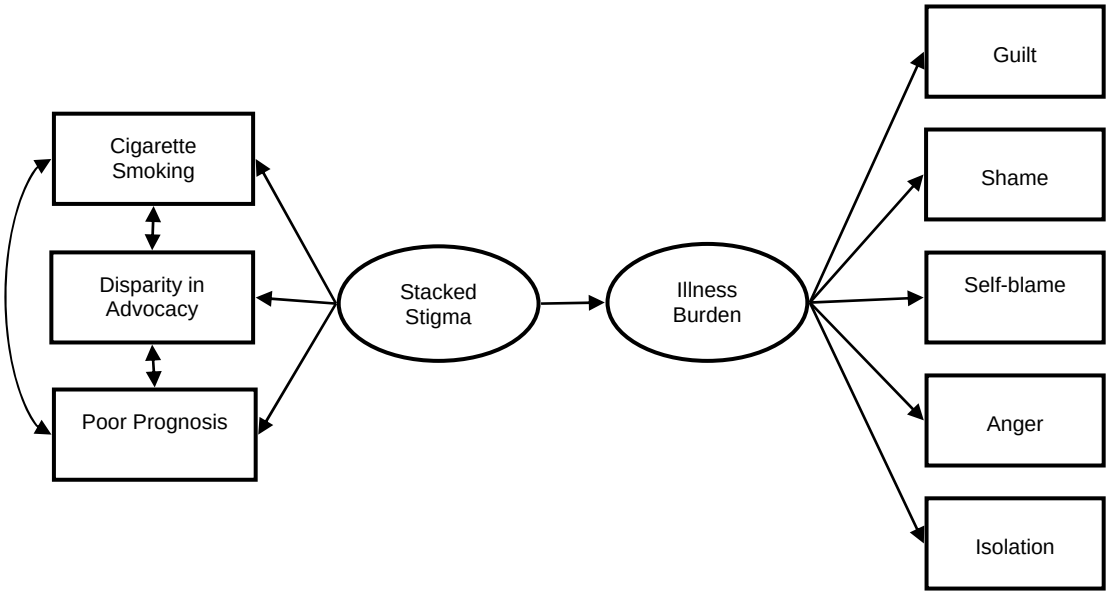
Measures and Analysis

Each oncology social worker participated in an individual, audiotaped, semi-structured telephone interview that lasted between 20 and 95 minutes. The interviewer asked the participants to describe any differences they observed between their patients diagnosed with lung cancer and patients with other cancers. The interview stopped when the participant stated that there was no further information to provide. A constant comparison method of data analysis continued throughout the data collection period. This allowed the researcher to learn from the data and guided the research project towards the theories. Once data saturation was achieved, and there were no further gaps, the theories were developed and the theoretical sampling was halted.

Results

Several core categories emerged from the data. However, this article will focus on three of them: stigma due to cigarette smoking, disparity in advocacy efforts and poor prognosis. These have led to the preliminary development of a theory of *stacked stigma*. Stacked stigma is defined as a set of two or more stigmas that initiate with the illness, are linked to each other, and strengthen and perpetuate the stigma experience, consequently increasing the illness burden (Conlon, Gilbert, Jones, & Aldredge, 2010). Stigma related illness burden can be expressed as guilt, shame, self-blame, anger and isolation (Heijnders & van der Meij, 2006; Weiss, 2007). Figure 1 illustrates a conceptual model of stacked stigma in the lung cancer experience.

Figure 1. Conceptual Model of Stacked Stigma in the Lung Cancer Experience.



Stigmas due to cigarette smoking, disparity in advocacy efforts and poor prognosis initiate with the lung cancer diagnosis, are linked to each other, and strengthen and perpetuate stigma in the lung cancer experience. For example, in light of the minimal advocacy efforts for lung cancer, merely observing the advocacy efforts for other cancers can be stigmatizing for those with lung cancer. This is demonstrated in the quote below:

> *And, my lung cancer patients would receive things about this breast cancer run and that breast cancer run and that resource, you know, for Leukemia and Lymphoma, and different things like that. There was just nothing for lung cancer. There just wasn't the same kind of outpouring for lung cancer. Patients would be frustrated with that. And, they were frustrated with the lack of resources. And, that played into that feeling of this disease being stigmatized.*

Individuals seeking justification for the disparity in advocacy efforts might link the disparity to cigarette smoking as demonstrated below:

> *Just for example . . . there seems to be so much awareness and advocacy [for women with breast cancer] at a national level and in the media that really helps women in the breast cancer population to understand what it's about, what they deserve, the level of care they deserve, and the quality of care they deserve. That they have rights. They can advocate for themselves. It's just this huge media campaign, I suppose, empowering women who are going to be seeking treatment for their breast cancer . . . that just doesn't happen for women with lung cancer, or anybody with lung cancer because of the stigma related to the whole smoking issue.*

These experiences increase the illness burden. As the oncology social worker notes below, her patients felt ignored and pushed aside due to the disparity in advocacy efforts:

> *"We just had a lung cancer conference here a couple of months ago. The lack of resources and media attention was something many patients mentioned. They felt ignored and that people pushed them to the side because they did something to cause their lung cancer. So, why should anyone spend money on us? That was hard because every once in a while I would hear this in my practice. However, this was a group forum, and once somebody said it, everybody started saying, 'that's exactly how I feel!' It was really upsetting to hear that,"* (Conlon et al., 2010).

Conclusion and Implications for Future Work

Individuals diagnosed with lung cancer not only have the misfortune of a devastating disease, but also must endure the impact of its accompanying stigma. This grounded theory work suggests that lung cancer stigma goes beyond that of cigarette smoking; there is a stacked stigma effect. A preliminary theory of stacked stigma was developed from the data that includes stigma due to disparity in advocacy efforts and poor prognosis in addition to stigma due to cigarette smoking. These stigmas are initiated by the lung cancer diagnosis, link to each other, and strengthen and perpetuate stigma in the lung cancer experience. The next step includes testing this theory using structural equation modeling.

Our social work code of ethics states that "social workers should act to expand choice and opportunity for all people, with special regard for vulnerable, disadvantaged, oppressed, and exploited people and groups" (National Association of Social Workers, 2008, Section 6.04(b)). Thus, the results of this grounded theory study will be used to bring attention to the prevalence and depth of stigma in the lung cancer experience and advocate for resources and funding at parity with breast, prostate and colon cancers. Future research on interventions that reduce the effects of stigma is strongly encouraged.

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